

A PATIENT GUIDE FOR APPROPRIATE MEDICATION USE AFTER SOLID ORGAN TRANSPLANT.

### Introduction

# Why do you need to take transplant medications?

The immune system is a collection of organs and cells that recognizes and protects your body from foreign substances and diseases. The immune system recognizes your transplant as foreign and will try to attack or damage the new organ. This is known as rejection. Therefore, antirejection or immunosuppressive medications must be taken daily and exactly as prescribed for life in order to prevent rejection.

These medications and the potential side effects are listed in this packet. It is important to remember that not everyone experiences these side effects. Plus, most of the side effects can be relieved or at least lessened by making adjustments to the medications. Thus, it is important to notify the health-care professional monitoring your transplanted organ

if you have any of the listed side effects. However, you must <u>NEVER</u> change the dosage or stop taking these medications without specific instructions from your transplant team.

There are many transplant medications, and each medication has specific or unique instructions for use. As a result, it can be difficult to keep yourself and your medication regimen organized. Therefore, this packet also reviews tips for taking your immunosuppressive medications. Your physician, transplant coordinator, and pharmacist are other excellent resources for medication education.

Also, immunosuppressive medications increase your risk for



infections. Consequently, this packet lists actions you can take or measures to avoid in order to lessen the risk for infections along with vaccination advice.

#### Tacrolimus

- o Names
  - Generic Drug Name: tacrolimus (pronunciation: ta kroe li mus)
  - Brand Name(s): Prograf®, Hecoria®
  - Alternate Name/Abbreviation(s): FK 506
- o How It Works
  - Blocks the growth and production of active immune cells (T-lymphocytes) in the blood. T-lymphocytes can cause rejection of your transplanted organ.
- o Potential Side Effects
  - Headache
  - Tremor
  - Burning & tingling of hands and/or feet
  - High blood pressure
  - High blood sugar
  - Impaired kidney function
  - Electrolyte changes: high potassium levels & low magnesium levels
  - Hair loss
  - Diarrhea
- Serious Side Effects
  - Call your doctor immediately if you experience any of the following:
    - Tremors
    - Seizures
    - Yellowing of the skin or eyes
    - Severe or continued headache with confusion, tremors, or changes in vision
- Important Notes
  - Tacrolimus must be monitored based on the level drawn from the blood. This blood level must be drawn about 12 hours after the last dose in order to be accurate. this is known as a "trough" level.
  - DO NOT take your tacrolimus the morning before you are scheduled to have your blood drawn. Instead bring your tacrolimus to clinic, and take it immediately AFTER you blood is drawn. On all other days, try to take your tacrolimus around the same time each day, and take each dose about 12 hours apart.
  - Your goal trough level will change depending on how far you are from transplant, your type of transplant, your infections risk, or other side effects you are experiencing. Based on the trough level in your blood, the transplant team will either increase your dose or decrease your dose or leave the dose the same.
  - Capsules must be swallowed whole. Do not crush, chew, or cut the medication prior to taking.
  - This medication can be taken with or without food, but be consistent. Always take with food OR always take on an empty stomach.

## Immunosuppression

A Review

#### Cyclosporine

- Names
  - Generic Drug Name: cyclosporine (pronunciation: Sye kloe spor een)
  - Brand Name(s): Neoral® (Modified), Gengraf® (Modified), Sandimmune®
  - Alternate Name/Abbreviation(s): CSA
- o How It Works
  - Blocks the growth and production of active immune cells (T-lymphocytes) in the blood.
     T-lymphocytes can cause rejection of your transplanted organ.
- o Potential Side Effects
  - Headache
  - Tremor
  - Burning & tingling of hands and/or feet
  - High blood pressure
  - High blood sugar
  - Impaired kidney function
  - Increased hair growth
  - Swollen or inflamed gums
  - High uric acid levels (Gout)
- o Serious Side Effects
  - Call your doctor immediately if you experience any of the following:
    - Tremors
    - Seizures
    - Swollen or inflamed gums
    - Yellowing of the skin or eyes
    - Severe headache with confusion or changes in vision
- Key Notes
  - Cyclosporine must be monitored based on the level drawn from the blood. This blood level must be drawn about 12 hours after the last dose in order to be accurate. This is known as a "trough" level.
  - Therefore, DO NOT take your cyclosporine the morning before you are scheduled to have your blood drawn. Instead bring your cyclosporine to clinic, and take it immediately AFTER you blood is drawn. On all other days, try to take your cyclosporine around the same time each day, and take each dose about 12 hours apart.
  - Your goal trough level will change depending on how far you are from transplant, your type of transplant, your infections risk, or other side effects you are experiencing. Based on the trough level in your blood, the transplant team will either increase your dose or decrease your dose or leave the dose the same.
  - Capsules must be swallowed whole. Do not crush, chew, or cut the medication prior to taking.
  - This medication can be taken with or without food, but be consistent. Always take with food OR always take on an empty stomach.

#### Sirolimus

- Names
  - Generic Drug Name: sirolimus (pronunciation: sir oh li mus)
  - Brand Name(s): Rapamune®
- o How It Works
  - Blocks the growth and production of active immune cells (T-lymphocytes) in the blood.
     T-lymphocytes can cause rejection of your transplanted organ.
- o Potential Side Effects
  - High triglyceride levels
  - Increased spilling of proteins into the urine by the kidney (proteinuria)
  - Low red blood cell & platelet counts
  - Impaired wound healing
  - Mouth sores or ulcers
  - Swelling of lymph tissue
- o Serious Side Effects
  - Call your doctor immediately if you experience any of the following:
    - Cough
    - Pale skin
    - Unusual bleeding or bruising
    - Sores inside mouth
- Key Notes
  - Sirolimus is one of the immunosuppressive medications that must be monitored based on the level drawn from the blood. This blood level must be drawn about 24 hours after the last dose in order to be accurate. This is known as a "trough" level.
  - Therefore, DO NOT take your sirolimus the morning before you are scheduled to have your blood drawn. Instead bring your sirolimus to clinic, and take it immediately AFTER you blood is drawn. On all other days, try to take your sirolimus around the same time each day, and take each dose about 24 hours apart.
  - Your goal trough level will change depending on how far you are from transplant, your type of transplant, your infections risk, or other side effects you are experiencing. Based on the trough level in your blood, the transplant team will either increase your dose or decrease your dose or leave the dose the same.
  - This medication can be taken with or without food, but be consistent. Always take with food OR always take on an empty stomach.

#### Mycophenolate

- Names
  - Generic Drug Name: mycophenolate mofetil, mycophenolic acid (pronunciation: Mye koe fen oh late)
  - Brand Name(s): Cellcept®, Myfortic®
- o How It Works
  - Blocks the growth and production of active immune cells (T-lymphocytes) in the blood.
     T-lymphocytes can cause rejection of your transplanted organ.
- o Potential Side Effects
  - Low white blood cell count (immune cell) & platelets
  - Stomach pain or cramping
  - Nausea or vomiting
  - Diarrhea
- Serious Side Effects
  - Call your doctor immediately if you experience any of the following:
    - Abdominal pain
    - Black, tarry stools
    - \* Blood in the urine
    - Sores inside mouth
- Key Notes
  - Take with food to help lessen stomach upset.
  - Mycophenolic acid (Myfortic®) must be swallowed whole. Do not crush, chew, or cut the medication prior to taking.

#### Azathioprine

- Names
  - Generic Drug Name: azathioprine (pronunciation: ay za thye oh preen)
  - Brand Name(s): Imuran®
- How It Works
  - Blocks the growth and production of active immune cells (T-lymphocytes) in the blood.
     T-lymphocytes can cause rejection of your transplanted organ.
- o Potential Side Effects
  - Low white blood cell count (immune cell)
  - Low red blood cell & platelet counts
  - Cold hands and feet
  - Inflammation of the pancreas (pancreatitis)
  - Impaired liver function
  - Skin cancer
- Serious Side Effects
  - Call your doctor immediately if you experience any of the following:
    - Blood in urine
    - Bloody or dark, tarry stools
    - Fever
    - Mouth sores
    - Skin rash
    - Unusual bleeding or bruising
    - Yellowing of the skin or eyes
- Key Notes
  - If you have gout <u>AVOID</u> taking allopurinol as it interferes with the metabolism of azathioprine. Tell your doctor you are taking azathioprine, and he can prescribe an alternative medication to manage gout.
  - This medication can be taken with or without food, but be consistent.

#### Prednisone

- Names
  - Generic Drug Name: prednisone (pronunciation: pred ni sone)
  - Brand Name(s): Deltasone®, Meticorten®, Orasone®
- o How It Works
  - Decreases inflammation and blocks the growth and production of active immune cells (T-lymphocytes) in the blood. T-lymphocytes can cause rejection of your transplanted organ.
     Inflammation can further damage the organ during rejection.
- o Potential Side Effects
  - Bone weakness (Osteoporosis)
  - High blood sugar
  - Causes your body to hold onto more salt and water
  - Swelling (Edema)
  - High blood pressure
  - Increased appetite
  - Weight gain
  - Puffy ("moon-faced") appearance
  - Mood changes (Depression, Anxiety)
  - Sleep disturbances (Insomnia)
  - Increased hair growth
  - Acne
  - Stomach irritation or ulcers
- o Serious Side Effects
  - Call your doctor immediately if you experience any of the following:
    - Black or tarry stool
    - Cold or infection that lasts a long time
    - Muscle weakness
    - Skin rash
    - Swollen face, lower legs, or ankles
    - Vision problems
- Key Notes
  - Your body makes a hormone that is similar to prednisone, and your body may stop making this hormone while you are on prednisone. For this reason, abruptly stopping or missing multiple days of steroid therapy can be life-threatening especially if you are under extreme stress (such as infection or surgery).
  - Take with food or milk to help prevent irritation to stomach lining.



# What do you do if you miss a dose?

Read the following section carefully as each medication has unique instructions for missed doses. If you miss a dose, here is what you should do:

- Mycophenolate:
- If you take mycophenolate twice a day: if you forget to take a dose and it is less than 6 hours since the missed dose, take the missed dose and get back on schedule with the next dose. If it has been greater than 6 hours since the missed dose then skip the one dose, and get back on schedule with the next dose.
- If you
  mycophenolate four
  times a day: if you forget
  to take a dose and it is
  less than 2 hours since
  the missed dose, take

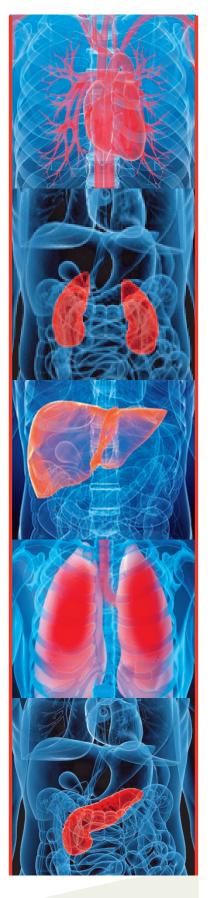
the missed dose and get back on schedule with the next dose. If it has been greater than 2 hours since the missed dose then skip the one dose, and get back on schedule with the next dose.

- ► Tacrolimus & Cyclosporine:
- If you forget to take your tacrolimus or cyclosporine and it is less than 6 hours since the missed dose, take the missed dose and get back on schedule with the next dose. If it has been greater than 6 hours since the missed dose then skip the one

dose, and get back on schedule with the next dose.

- ► Sirolimus, Prednisone, & Azathioprine:
- If you forget to take your sirolimus, prednisone, or azathioprine take the missed dose when you remember and get back on schedule with the next dose.

DO NOT double up on missed doses. This can lead to serious toxicities.



### Herbal and Over-the-Counter (OTC) Medications

Currently, the U.S. Food and Drug Administration (FDA) does NOT regulate the production and labeling of herbal supplements. The use of these drugs can have serious negative impact on the transplanted organ and your immunosuppressive medications. To be safe, all transplant recipients should <u>AVOID</u> herbal supplements. Similarly, certain OTC medications can interfere with the function of transplanted organs. Thus, be sure to read the active ingredient label carefully, and do NOT take any OTC products without prior approval from the transplant team. The following is a list of concerns with common OTC products:

- ♦ If you have a kidney, heart, or lung transplant <u>AVOID</u> non-steroidal anti-inflammatory drugs (NSAIDS) such ibuprofen (Motrin® and Advil®) and naproxen (Aleve®) and all combination products containing these agents.
- ♦ If you have a liver transplant, do NOT take acetaminophen (Tylenol®) containing products without prior approval from your transplant team.
- ♦ Do NOT take laxatives containing magnesium oxide or antacids containing calcium carbonate within 2 hours of taking your immunosuppressive medications. They can prevent the absorption of other medications.







Be sure your doctor is aware of your transplant medications before starting the following common medications. They interfere with the metabolism of certain transplant medications and require more frequent trough level monitoring or adjustments in the dosage of your transplant medications:

- Antibiotic medications:
  - Clarithromycin (Biaxin®); Erythromycin (E.E.S. ®, E-Mycin®, Erythrocin®)
- Antifungal medications:
  - Clotrimazole (Lotrimin®); Fluconazole (Diflucan®); Itraconazole (Sporanox®); Voriconzaole (Vfend®); Ketoconazole (Nizoral®)
- Antiviral medications: HIV or Hepatitis C medications
- Blood pressure and heart medications:
  - Diltiazem (Cardizem®, Dilacor®, Tiazac®); Verapamil (Calan®, Covera®, Isoptin®, Verelan®)

### Immunosuppression General Tips

- 1. Learn everything you can about your medicines. Your physician, transplant coordinator, and pharmacist can help.
- ALWAYS carry an updated list of your medicines and their doses in your wallet or purse. Share this list with all of your doctors.



- 3. AVOID grapefruit juice and pomegranate juice and products containing grapefruit or pomegranate because they can interfere with the immunosuppression medications.
- 4. Always check with your transplant team before taking any new medicines, even the ones you buy over the counter, including vitamins.

- 5. Do not take all your medicines at one time because it is more convenient. The doses are spread out to make sure the proper drug level is in your body. Ask your transplant team to help set up your medicine times to fit your schedule.
- 6. Organization: To help organize your medicines, use tools such as pillboxes that have individual compartments labeled with the days of the week. Use an alarm clock, watch, or charts to remind you of the times for medicines. Set up a time each week to organize your medicines for the whole next week.

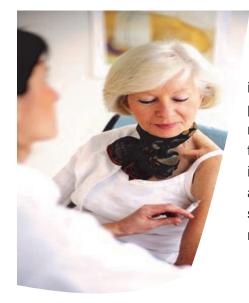


7. Refills: Keep track of how much medicine you have left. Don't ever run out, even one dose. Mark your calendar so you remember to reorder your medications ahead of time.



- 8. Travel: Always keep extra doses of your medicine with you when you travel in case you are delayed or miss a plane, train, or bus.

  Never pack your medications in your luggage. Always carry them with you or they may get lost or be exposed to temperatures that are too cold or too hot.
- 9. Limit your sun exposure. Use a sunscreen of at least 30 SPF to avoid skin cancers because transplant medications can increase sun sensitivity and your risk for certain skin cancers.





### NOT ALL VACCINES ARE APPROPRIATE AFTER TRANSPLANT:



Live virus vaccines that transplant patients should <a href="NEVER">NEVER</a> receive:

- Measles, Mumps, Rubella
- Oral polio
- Varicella/Chicken Pox
- Smallpox
- Yellow Fever
- Typhoid
- Bacilli Calmette-Guerin

### **Infections**

Another side effect of immunosuppressive medications is that they can increase your risk for infections. Your body's immune system is important in preventing or attacking infections. However, because the immunosuppressive medications block the immune system and prevent rejection, these medications also block the immune system's ability to fight off infections. This risk for infection is highest for the first 6 months following your transplant, but you will always be at higher risk compared to an individual that is not taking immunosuppressive mediations. There are many actions you can take to lessen the risk for infections such as those listed below.

#### Measures to reduce infection risk:

- You should wash your hands with soap and water for at least 15 seconds before meals, after using the bathroom, if they become contaminated, and if you have had a lot of contact with other people and/or public objects.
- Avoid touching your eyes, nose, and mouth if your hands are not clean.
- Avoid direct contact with people that are sick.
- \* Practice safe sex.

- Avoid smoking and exposure to second hand smoke.
- Do not share eating or drinking utensils, razors, or toothbrushes, even with your family members.
- Wear gloves when gardening or doing farm work and shoes when walking outside.
- Wear protective clothing and insect repellent when outdoors.
- \* If you are a diabetic, work with your physician to keep blood sugars under good control.

### **VACCINATION**

In addition to practicing these measures, transplant patients should receive the flu vaccine every year prior to flu season barring approval by your transplant team. Transplant recipients should also receive the pneumonia vaccine every 5 years. However, transplant patients should <u>NEVER</u> take the aerosol version of the flu vaccine or any other live vaccine. Below is a list of acceptable vaccines.

Dead virus vaccines that transplant patients CAN SAFELY RECIEVE:

- Influenza (Flu) (except the aerosolized form)
- Pneumococcal
- Diptheria /Tetanus (DT) booster
- Tuberculosis
- Hepatitis A and B



